

RUNNING HEAD: Caregiver Support Services

Availability of caregiver support services: Implications for implementation of the National
Family Caregiver Support Program

Stephanie Whittier, Andrew Scharlach & Teresa S. Dal Santo

ABSTRACT

This study examines the scope and range of existing resources for family caregivers, from the perspective of the Area Agencies on Aging (AAAs) which are charged with implementing Title III-E of the reauthorized Older Americans Act. California is used as a case example because of its substantial experience in providing caregiver support services. In particular, we examine the extent and adequacy of resources available in California corresponding to each of the five Title III-E service areas, utilizing data from AAA Area Plans, a follow-up survey of AAAs, and an internet search. AAAs identified more than 276 providers of caregiver support services, and our internet search identified another 195. Nearly two-thirds of these programs offer access to respite care, while other support services (e.g. counseling, training, support groups) are less often available. Service gaps most frequently identified included culturally and linguistically appropriate caregiver services, transportation, respite care, financial assistance, and services in rural areas. These findings suggest the need for enhanced efforts to improve the service network for supporting family caregivers, as states implement the National Family Caregiver Support Program.

KEYWORDS: Needs Assessment, Program Planning, Family Caregiving, Area Agencies on Aging

Stephanie Whittier, MSW, was a graduate student researcher at the Center for the Advanced Study of Aging Services, University of California, Berkeley, School of Social Welfare, at the time of this research; she currently is a management intern with the Department of Health and Human Services' Emerging Leaders Program at the U.S. Administration on Aging.

Andrew Scharlach, Ph.D., is the Kleiner Professor of Aging, and Director, Center for the Advanced Study of Aging Services at the University of California, Berkeley, School of Social Welfare.

Teresa S. Dal Santo, Ph.D., is Senior Research Associate, Center for the Advanced Study of Aging Services. Dr. Dal Santo serves as project director of the California Family Caregivers Support Project.

This research was conducted through an interagency agreement with the California Department of Aging.

INTRODUCTION

Family caregivers have always been the mainstay underpinning long-term care for older persons. Among non-institutionalized persons needing assistance with activities of daily living, two-thirds depend solely on family and friends and another one-fourth supplement family care with services from paid providers (Lui, Manton, and Aragon 2000). Yet, caring for a disabled family member can be challenging, potentially impacting caregivers' health, mental health, work, social relationships, and quality of life (Ory et al. 1999; Pruchno and Postashnik 1998; Schulz and Beach 1999). To help support families in maintaining their caregiver roles for their older family members who are ill or who have disabilities, and for older adults who have primary care responsibilities for young children, Congress created the National Family Caregiver Support Program (NFCSP) (Title III-E of the OAA 2000 Reauthorization).

The NFCSP marks a first-of-a-kind opportunity to meet the needs of family caregivers through a federally-based program that is administered by the states. The NFCSP, intended to provide critical support needed by caregivers, initially included \$125 million of funding through Title III-E of the reauthorized Older Americans Act. The five support service areas identified in the NFCSP include: (1) information to caregivers about available services; (2) assistance to caregivers in gaining access to these services; (3) individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles; (4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and (5) supplemental services, on a limited basis, to complement the care provided by caregivers.

The NFCSP is being implemented in a manner that provides significant flexibility to the states. The federal funds have been awarded to State Units on Aging who work in partnership

with Area Agencies on Aging (AAAs) to develop plans for meeting the needs of local caregivers. Preliminary state NFCSP implementation plans and policies for funding programs vary in the range and scope of Title III-E support services provided. However, most states are emphasizing respite and supplemental services (Feinberg, Newman, and Van Steenberg 2002) while some states have integrated caregiver support into their home and community-based service (HCBS) systems (Coleman and Dize, 2002). This flexibility in implementation has promoted a variability of service options that might paradoxically limit, rather than enhance, choices for family caregivers (Feinberg et al. 2002).

An essential component of AAA planning responsibilities for implementing the NFCSP at the local level is an analysis of existing caregiver resources, including the availability, appropriateness, accessibility, and adequacy of existing services (California Code of Regulations Article 3, §7302). A comprehensive analysis of the scope and range of existing community resources can help AAAs to develop plans and allocate resources to better respond to local caregiver needs in the most effective and efficient manner possible, whether by reducing barriers to accessing existing services, supplementing services as needed, or creating new services where none exist.

In this study, we examine the range and adequacy of existing caregiver resources in California from the perspective of the AAAs who are charged with implementing the NFCSP. California provides a particularly interesting and useful framework from which to examine the planning and delivery of caregiver services because of its lengthy history of state-funded caregiver support activities. California has a well-established array of potential resources for caregivers, offered through a broad range of public, not-for-profit, and private service providers, including religious, social, and health care organizations; and, California has been identified as a

state whose programs represent a best practice in caregiver support (Feinberg et al. 2002). A recent survey of California households estimated that close to 16% of households were involved in providing care to someone age 50 or older (Scharlach et al. 2003), comparable to a 1997 national study which indicated that approximately 17% of all U.S. households with a telephone contain at least one caregiver (National Alliance for Caregiving and the American Association of Retired Persons 1997). Moreover, AAAs in California provide services for the largest and most diverse senior population of any state within the U.S. As of the year 2000, close to 3.6 million Californians were 65 years of age and above, of whom approximately 70% were White, 13% were Hispanic or Latino, 10% were Asian, 5% were Black, and 2% were of some other or multiracial identity (U.S. Census 2000).

This study examines the extent and adequacy of the existing caregiver support network, in terms of the specific service types specified in Title III-E of the Older Americans Act. Previous empirical and conceptual analyses have spoken generally about caregiver supports and model programs (Coleman and Dize 2002; Feinberg, et al. 2002; Scharlach et al. 2001) or have focused only on one type of support. This study considers all five types of Title III-E services from the perspective of the AAAs, which are charged with implementing and assuring the adequacy of these services. In so doing, this research fills a void in the family caregiving literature by providing a first look at the implementation of new federal caregiver support policies at the local level and the adequacy of the existing caregiver resource network in this country to implement those policies. The findings of this research provide insight into the availability of caregiver supports and the areas in which additional supports may need to be developed, providing important information to states regarding how best to target resources as they continue to implement the National Family Caregiver Support Program.

METHODS

Several research methods were utilized in an effort to identify existing services and service gaps for caregivers of individuals over age 60, including the following: a review of AAA Area Plan addenda submitted in 2001; a survey of California AAAs; and an internet search of caregiver support services in California. AAA Area Plan addenda (FY 2001 – 2005) for all 33 California AAAs were obtained from the California Department of Aging (CDA), and reviewed regarding local resources for caregivers. The California Department of Aging (CDA) periodically publishes official program memoranda that establish standard procedures and guidelines for the implementation of the programs and services that it administers through the AAAs. CDA Program Memo (PM) 01-10 is specific to the implementation of the NFCSP and the assessment of caregiver needs, and stipulates that the AAAs carry out an inventory of existing caregiver support services. AAA inventories were examined with regard to their specificity, number, and type of resources in each of the five NFCSP service areas, and presence of resources other than those specified under OAA Title III-E.

A survey questionnaire was designed to elicit the AAAs' experiences with the NFCSP after the first year of implementation and to expand upon the information provided in the NFCSP addenda submitted with the Area Plans the previous year. Each AAA was asked to list the major providers of caregiver services in its planning area and to provide a complete resource list of caregiver services, if available. The questionnaire also asked each AAA to review a list of possible services within each of the five Title III-E service categories and indicate those services that did not seem adequate to meet caregiver needs in the AAA's planning and service area (PSA). The list was developed from several sources, including: (1) Title III-E service definitions from the California Department of Aging program instructions (CDA, 2001), (2) AAA identified

service needs identified as listed in their Area Plan Addenda, and (3) services identified in the literature as effective interventions (Scharlach et al. 2001). For example, information services included outreach, community education classes, medical information and caregiver literature while respite services include adult day care and emergency, overnight, and in-home respite.

Analyses of the providers identified by AAAs, both in their addenda and surveys, included performing counts of identified providers by each Title III-E service category (information, access, caregiver support, respite and supplementary); providers could be categorized into more than one service category depending on the types of services offered. In addition, researchers further categorized the AAA-identified providers into one of the following types: Caregiver Resource Centers; adult day care and day respite programs; general community social service programs, such as support groups, senior centers, and faith-based organizations; public agencies with unspecified caregiver support services, such as “AAA” or In-Home Supportive Services; health care related organizations, such as Visiting Nurses; publicly funded case management programs, such as Linkages and Multipurpose Senior Services Program; disease-specific organizations, such as the Alzheimer’s Association; residential care and overnight respite providers; and legal services. Finally, from the survey list of caregiver services, the proportion of AAAs indicating a service inadequacy for meeting caregiver needs in their planning and service area was calculated.

The survey was distributed electronically to the directors of the 33 AAAs, with responses from 24 (73%) of the AAA directors or caregiver program directors. The responding AAAs are responsible for arranging and providing services for approximately 86% of California’s population age 65 or older. County-level data from the U. S. Census (2000) were used to compare responding AAAs with non-respondents, and the two groups were not found to differ

significantly with regard to the proportion of the population over the age of 65, below the poverty level, with a language other than English spoken at home, or with regard to population per square mile.

An internet search was conducted to augment the information obtained from the AAA addenda and questionnaires. The key words used to search for caregiver support services were: “caregiver,” “caregiving,” “caregiver services,” “caregiver support,” and “individual and family support.” The search included the California Department of Aging website, Area Agencies on Aging websites, other online resources accessed through AAA websites, and searches on a number of search engines (e.g., Google).

RESULTS

Caregiver Resources Identified

Our review of the 33 AAA addenda found that 14 of the addenda (representing 42% of AAAs) did not contain any type of inventory or mention of caregiver services; 11 addenda (33%) included a very brief discussion about the services available to family caregivers, but did not provide a detailed list of providers; five addenda (15%) described the range of caregiver support services available, but did not include any type of inventory; and, only three addenda (9%) included an inventory of available caregiver support services. The total number of caregiver resources included in these three addenda ranged from 3 to 26. A total of 155 caregiver services were identified by all 33 addenda.

Seventeen of the 24 AAAs responding to the follow-up survey identified additional caregiver support resources. The total number of caregiver resources identified through the survey by these 17 AAAs was 149, ranging from 1 to 27 (median = 7). A total of 304 caregiver support providers were identified by AAAs in their addenda or survey responses. This count

included 276 distinct providers, some of which were listed by more than one AAA. Our internet search uncovered an additional 195 caregiver support services not previously identified by the AAAs in their Area Plan addenda or responses to the follow-up survey. The number of additional resources we found on the internet for each AAA ranged from 1 to 32 (median = 3).

The distribution of identified caregiver support providers by NFCSP service category is summarized in Table 1 and described below. In many cases, the caregiver service providers supply more than one type of caregiver service.

[Insert Table 1]

Information to Caregivers About Available Services. AAAs identified a total of 107 informational resources on their Area Plan addenda or follow-up survey, representing 35% of all caregiver resources identified by the 33 AAAs. Each AAA identified from 0 to 10 informational resources (median = 2). Our internet search uncovered an additional 95 informational resources, ranging from 0 to 10 per AAA (median = 2), not previously identified by the AAAs.

Assistance to Caregivers in Gaining Access to Services. Seventy-nine (79) resources providing assistance accessing services were identified by AAAs, representing 26% of all caregiver resources identified by the 33 AAAs. Each AAA identified from 0 to 9 resources (median = 2). Our internet search uncovered an additional 64 access resources not previously identified by the AAAs (range 0 to 5, median = 2).

Counseling, Support Groups, and Caregiver Training. AAAs identified from 0 to 10 (median = 1) resources offering counseling, support groups, or caregiver training. A total of 76 counseling or support resources were identified by the AAAs, representing 25% of all identified providers. Our internet search uncovered an additional 49 (range 0 to 16, median = 0) of these counseling-related resources not previously identified by the AAAs.

Respite Care. AAAs identified a total of 190 resources offering respite care or assistance obtaining respite care, representing 63% of all caregiver resources identified by the AAAs. The number of resources identified by each AAA ranged from 0 to 23 (median = 4). Our internet search uncovered an additional 104 respite care providers (range 0 to 16, median = 2).

Supplemental Services. Each AAA identified from 0 to 9 (median = 2) resources providing or offering assistance in obtaining supplemental services, including home modification, home security and safety assistance, assistive devices, personal care, chores/homemaker services, nutrition programs, legal assistance, and friendly visiting. A total of 82 resources were identified, representing 29% of all caregiver resources identified by the AAAs. Our internet search uncovered an additional 87 (range 0 to 15, median = 2) of these types of services.

Caregiver Service Providers

Types of caregiver support service providers identified by AAAs, either in their Area Plan addenda or follow-up survey, were as follows: Caregiver Resource Centers (identified by 78% of AAAs); adult day care and day respite programs (67% of AAAs); general community social service programs (identified by 61% of AAAs); public agencies (52% of AAAs); health care related organizations (48% of AAAs); publicly funded case management programs (33% of AAAs); disease-specific organizations (27% of AAAs); residential care and overnight respite providers (24% of AAAs); and legal services (18% of AAAs).

Major Caregiver Service Gaps

The service gaps identified most often by the AAAs are summarized in Table 2. Multilingual or culturally-appropriate services were consistently identified as a major service gap across all the caregiver service categories. Languages in which information services were not

considered adequate included Russian, Farsi, Portuguese, Spanish, Lao, Mien, Cambodian, Korean, Chinese, and Hmong. One respondent noted that “trained and professional help to provide [counseling, support and training services] is in short supply for most of the ethnic groups.” Other service gaps identified by a majority of AAAs included: transportation, financial assistance, in-home workers and other community services in rural areas, and translation services (as barriers to service access); emergency, overnight, and in-home services (as barriers to respite); and one-time emergency cash (as a needed supplementary service). AAAs with a higher than average proportion of their population speaking a language other than English were found to report a greater number of service gaps ($t = 2.109$, $p = .05$, $df = 15.23$); however, the number of service gaps identified were not significantly associated with the proportion of the population age 65 or older nor the proportion with incomes below the poverty level.

[Insert Table 2]

DISCUSSION

This study represents the first statewide analysis of the scope and adequacy of existing caregiver resources for family caregivers, from the perspective of the Area Agencies on Aging (AAAs) which are charged with implementing Title III-E of the reauthorized Older Americans Act. The findings provide insight into the strengths and limitations of existing resources, and the need for local AAAs to enhance planning and service delivery efforts to meet caregiver needs.

Summary of Major Caregiver Resource Types

California has an extensive array of caregiver support programs to serve the estimated 1.8 million California households that provide assistance to someone over the age of 50 (Scharlach et al. 2003). Our analysis identified at least 471 distinct providers of caregiver support services statewide, and this number probably undercounts substantially the variety of caregiver support

services actually available. Of these, only 155 were identified in AAA Area Plans, with another 121 identified in a follow-up survey completed by 24 of the 33 AAAs and 195 identified through an internet search. To some extent, the large number of caregiver resources not initially identified by AAAs may reflect a learning curve as AAAs gain increasing knowledge and experience in the new area of caregiver service delivery.

Respite care was the type of service cited most often by AAAs (offered by 63% of 276 programs identified by AAAs). This reflects the central role of respite care in efforts to assist family caregivers. One of the important purposes of respite is to give family members time for personal activities and to temporarily relieve the stress they may experience while providing care for a family member. One in five caregivers say that the biggest difficulty they face in caregiving is the demand on their time or being unable to do what they want; this number increases among those providing higher levels of care (NAC/AARP 1997). Receiving in-home respite care has been associated with improved mood (Curran 1995) and reduced emotional distress (Harper et al. 1993). Additionally, caregivers experiencing severe adverse effects to their physical and emotional health have been found to benefit the most from respite care (Bass, Noelker, and Rechlin 1996). However, many of the respite care providers identified by the AAAs, including CRCs and social service programs, only provide assistance in accessing or paying for respite, and there undoubtedly are numerous local sources of in-home, day, and overnight respite, such as in-home workers or residential care facilities, that do not consider themselves as respite providers or do not have websites and may not have been identified in this study.

Major Caregiver Service Providers in California

Caregiver resources in California include Caregiver Resource Centers, adult day care centers, non-profit community-based social service organizations, AAAs and other public programs, health care providers, and disease specific organizations. Caregiver Resource Centers (CRCs) are the centerpiece of the state's caregiver support network. This single-entry network of 11 regional centers offers a broad range of services primarily to caregivers of adults with adult-onset brain impairments, including: information, advice, and referral; assessment of caregiver needs; long-term care planning and consultation; legal and financial consultation; mental health interventions such as counseling, support groups and psycho-educational groups; education and training programs; and respite care services. The CRCs use a consumer-directed care model, offering a flexible array of services to predominantly middle income families who are ineligible for other public benefits and cannot afford to pay for services out-of-pocket.

Adult day care centers also support caregivers by providing respite care, support groups, and supplemental services. Adult Day Health Care Centers in 34 of 58 California counties, and Alzheimer's Day Care Resource Centers in 23 counties, provide a safe, supervised, structured environment, including assessment and care planning, support groups and respite for caregivers, professional and lay training, and public education.

General community social service programs provide a wide array of caregiver support services such as information, care management, counseling, support groups, respite, and a range of supplemental services such as home visits, home-delivered meals, transportation, and homemaker services. In addition to their federally-mandated responsibility for assessing local needs and planning services for older adults and caregivers, Area Agencies on Aging themselves serve as a gateway to services. AAAs provide information and referral services nationwide through the national Eldercare Locator Program, while providing or supporting case management

and other publicly-sponsored programs which provide some respite and assist caregivers with the challenging task of arranging for services.

Health care organizations and providers were identified by nearly one-half of AAAs; moreover, caregivers consider them their primary source of support other than family and friends (Scharlach et al. 2003). Health care providers are an important potential resource for knowledge, education, and psychosocial support for patients and their families, and some health maintenance organizations offer advice lines or information and referral services. Of the 27% of AAAs identifying a disease-specific organization that offered caregiver services, the Alzheimer's Association was most often cited. The Alzheimer's Association has eight chapters in California offering caregivers information about available resources; published information regarding dementia, dementia care and caregiving issues; assessment and care management; support groups, caregiver trainings and community education; and financial assistance for respite.

Major Service Gaps

Overall, the most common gaps identified among general caregiver services consisted of multilingual and culturally-appropriate services, transportation, respite, financial assistance, and care in rural areas.

Culturally and linguistically appropriate services. The availability of multilingual and culturally appropriate services for caregivers was by far the most frequently identified gap in the current service network, and was identified in every category of NFCSP services by a majority of AAAs. Although the need for culturally and linguistically appropriate services is of particular concern for California, where the majority of the population already is non-White or Hispanic, rapid increases in the non-White and Hispanic elderly population predicted throughout the United States makes this an issue of national concern (Lee and Villa 2001).

Although the prevalence of family caregiving is higher in minority communities than in the non-Hispanic White population (National Alliance for Caregiving & the American Association of Retired Persons (NAC/AARP 1997), Latino and Asian/Pacific Islander caregivers are much less likely than non-Hispanic Whites and non-Hispanic Blacks to use caregiver support services (Scharlach et al. 2003). Moreover, due to different patterns in illness stemming from genetic, environmental, and lifestyle factors, minority caregivers may be caring for disabled elderly persons with different types or levels of functional disabilities than White and non-Hispanics (Aranda and Knight 1997). Cultural expectations related to family obligation, gender role expectations, and sense of duty can serve as barriers to utilization of caregiver support services among Hispanic caregivers (Morano and Bravo 2002). However, linguistic barriers can be overcome to some extent. Caregivers overwhelmingly indicate their preference for programs conducted in their native language, and studies have found that support groups for Spanish-speaking Hispanic populations conducted in Spanish are attended more regularly than those conducted in English (Morano and Bravo 2002).

Transportation. Transportation was one of the most commonly identified service gaps. The lack of available transportation serves as a barrier to accessing services both for themselves as well as for those for whom they are providing care. This is especially a problem in suburban and rural areas, where services may be far apart and public transportation limited. Moreover, in both rural and urban communities, transportation can be a challenge for older adults as both driving and taking public transportation become increasingly difficult (Wachs 2000).

Respite care. Respite care was available from nearly two-thirds of caregiver support providers. Yet, in many cases, the providers offered assistance in locating or paying for respite through CRCs or a care management programs rather than direct provision of respite services.

Emergency, unplanned, overnight, and weekend respite, especially in the care recipient's home, were often identified as major service gaps. Moreover, overnight respite care apparently is much less available than day respite.

Appropriate utilization of existing respite services is an issue, as well. Many caregivers choose to not use respite, use it only in small amounts, or use it only late into the care process. These service use patterns may stem from multiple sources, including a view by caregivers that respite services are inappropriate for mildly impaired care recipients, inadequate marketing of respite services to caregivers, and caregivers' not perceiving a need for respite for their relative or themselves. For those caregivers aware of and seeking respite care, cost is a critical factor prohibiting utilization (Zarit 2001).

Financial assistance. While financial assistance for caregivers exists in the United States, it provides more symbolic relief than that found in other countries. At least 15 states offer tax credits to individuals caring for a dependent parent. California, for example, instituted a \$500 tax credit for caregivers with AB 2268, the Dependent Parent Tax Credit, in 2000. Eligible for California's tax credit are primary caregivers of individuals certified by a physician as being unable to perform at least three activities of daily living (ADLs), or individuals requiring substantial supervision who are unable to perform at least one ADL due to cognitive impairment.

While tax credits send the message that states recognize the caregiver's work as important and valuable, they do not go far in easing the financial burden placed on caregivers (Scharlach 2001). NFCSP funding for California in fiscal year 2001/02, for example, totaled \$10.8 million or approximately eight dollars per eligible household. By comparison, Australia pays \$180 per week to caregivers unable to engage in paid work due to their caregiving responsibilities, and \$41 per week to any individual providing care to a disabled individual.

Almost 60% of Australian caregivers receive financial support through one of these programs (Department of Family and Community Services 1999).

Care in rural areas. Generally, rural areas are thought to be at a disadvantage in the availability of health and social services. For example, it has been found that elderly persons who are incontinent and live in rural areas are more likely to be institutionalized in a nursing home than their urban counterparts who benefit from community-based programs to assist older adults which are unlikely to exist in small towns and rural communities (Coward, Horne, and Peek 1996). In terms of social services, it appears that the amount of federal dollars received to support Older American Act programs is considerably lower in rural areas as compared with the metropolitan areas (Nelson 1983). This problem of under supply and under funding is compounded by the greater need in rural areas given the generally lower per capita income, high rates of chronic illness among elderly residents, and fewer young and adult-aged adults to provide care due to employment-related migration (Buckwalter and Davis 2001).

Implications for Policy and Planning

Under the reauthorized Older Americans Act of 2000, State Units on Aging (SUA) and AAAs throughout the U.S. are given responsibility for meeting the needs of family caregivers, as well as their traditional population of older persons. Our review of AAA Title III-E Area Plan addenda, responses to the follow-up survey, and internet search underscore some of the challenges experienced by AAAs as they attempt to identify local services to meet caregiver needs, in the brief timeframe envisioned by the OAA reauthorization. Generally, AAA planning efforts do not seem to include a full consideration of the range of existing services or service gaps, as evidenced by the many caregiver resources not included in the AAA Area Plan addenda which were identified by AAA survey respondents and in our internet review. Without a

complete analysis of existing caregiver resources, including the availability, appropriateness, accessibility, and adequacy of existing services, AAAs will be unable to coordinate NFCSP planning efforts with other public HCBS programs and with the efforts of business, religious, ethnic, social services and community organizations in order to utilize OAA funds most efficiently (Coleman and Dize 2002). Indeed, service gaps identified in AAA addenda differed from those identified by AAA survey respondents, and also differed from those identified by caregivers themselves (Kietzman, Scharlach, and Dal Santo [in press]; Scharlach et al. 2003).

These findings are consistent with the preliminary experiences of other states in providing caregiver support services (Feinberg et al. 2002), typically including a patchwork caregiver support system, multiple funding sources, divergent eligibility criteria, and different types of services provided. Across a number of states, respite care and supplemental services are seen as the top service needs of family caregivers. Because Title III-E funds are insufficient to meet the multifaceted needs of family caregivers, many states rely on public home and community-based service waivers to augment NFSCP respite care benefits.

Our findings regarding limitations in AAAs' ability to identify caregiver resources and overcome service barriers may reflect a learning curve as AAAs gain increasing knowledge and experience in the new area of caregiver service delivery. This finding is supported by the experiences of other states that find providing explicit support for family caregivers represents a paradigm shift from the AAAs' traditional population (Feinberg et al. 2002). It also may reflect AAAs' difficulty collecting and utilizing information about caregiver needs to develop service plans (Kietzman et al. [in press]). Challenges associated with community planning have been noted previously in the literature, especially regarding needs assessment, effective decision-making and priority-setting (Williams and Yanoshik 2001). Many organizations, working with a

sense of urgency to address widespread community problems, develop programs without using readily available community resources or view them as unrelated (Amodeo and Gal 1997).

In addition, the flexibility in the national implementation of NFCSP has promoted a variability of service options that may have limited, rather than enhanced, choices for family caregivers (Feinberg et al. 2002). Two-thirds of the caregiver service providers identified in this analysis offer respite care; however, counseling, training, support groups, and other services which may help prevent or delay negative consequences of caregiving were less commonly offered. More research, planning and policy efforts are needed to determine caregiver service preferences, and the effectiveness of various support services for caregivers and care recipients at different phases of caregiving over time.

CONCLUSION

The National Family Caregiver Support Program, Title III-E of the reauthorized OAA, provides AAAs with opportunities to expand services to meet the diverse and complex needs of family caregivers in their communities. However, local implementation requires a careful analysis of the scope and adequacy of the existing caregiver support service network, in order to target federal and state resources most effectively. While caregiver support services are provided by a broad range of public, not-for-profit, and private service providers, major service gaps exist in areas such as linguistically and culturally appropriate services, transportation, emergency, overnight and weekend respite, financial assistance, and care in rural areas. Overcoming these service gaps and establishing a comprehensive caregiver service network will require collaboration and coordination among formal and informal networks, public and private entities, and local and state systems.

REFERENCES

- Amodeo, M., and C. Gal. 1997. Strategies for ensuring use of needs assessment findings: Experiences of a community substance abuse prevention program. *The Journal of Primary Prevention* 18: 227-242.
- Aranda, M., and B. Knight. 1997. The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist* 37: 342-354.
- Bass, D., L. Noelker, and L. Rechlin. 1996. The moderating influence of service use on negative caregiving consequences. *Journal of Gerontology: Social Sciences* 51B: S121-S131.
- Buckwalter, K., and L. Davis. 2001. *Elder caregiving in rural communities* [online]. NFCSP Issue Brief, Iowa: Administration on Aging [cited 1 May 2003]. Available from World Wide Web: (<http://www.aoa.gov/alzheimer/carenetwork/issuebriefs0302/issuebriefs.html>)
- California Code of Regulations (CCR). Title 22. Social Security. Division 1.8. California Department of Aging. Chapter 3. Article 3. §7302.
- California Department of Aging (CDA). (2001, July 3). Program Memo 01-11: Program Data Reporting Requirements -Family Caregiver Support Program. Sacramento, CA.
- Coleman, B., and V. Dize. 2002. *Systemic development of the Family Caregiver Support Program: Considerations for the service package*. Washington, DC: National Association of State Units on Aging.
- Coward, R., C. Horne, and C. Peek. 1996. Predicting nursing home admissions among incontinent older adults: A comparison of residential differences across six years. *The Gerontologist* 35: 732-743

- Curran, J. 1995. Current provision and effectiveness of day care services for people with dementia. *Reviews in Clinical Gerontology* 5: 313-320.
- Department of Family and Community Services. 1999, July. *A carer's guide to: Financial support, respite co-ordination, and information services* [Brochure]. Australia: Jocelyn Newman & Bronwyn Bishop.
- Feinberg, L., S. Newman, and C. Van Steenberg. 2002. *Family caregiver support: Policies, perceptions and practices in 10 states since passage of the National Family Caregiver Support Program*. Washington, DC: Family Caregiver Alliance.
- Harper, D., P. Manasse, O. James, and J. Newton. 1993. Intervening to reduce distress in caregivers of impaired elderly people: A preliminary evaluation. *International Journal of Geriatric Psychiatry* 8: 139-145.
- Kietzman, K., A. Scharlach, and T.S. Dal Santo. In press. Local needs assessment and planning efforts for family caregivers: Findings and recommendations. *Journal of Gerontological Social Work*.
- Lee, R. and V. Villa. 2001. *Population aging in California*, SB-910 report, Berkeley, CA: University of California, California Policy Research Center.
- Lui, K., K. Manton, and C. Araon. 2000. Changes in home care use by disabled elderly persons: 1982-1994. *Journal of Gerontology: Social Sciences* 55B: S245-S253.
- Morano, C., and M. Bravo. 2002. A psychoeducational model for Hispanic Alzheimer's disease caregivers. *The Gerontologist* 42: 122-126.
- National Alliance for Caregiving & the American Association of Retired Persons (NAC/AARP). 1997, June. *Family Caregiving in the U.S.: Findings from a National Survey*. Washington, DC: Authors.

- Nelson, G. M. 1983. A comparison of Title XX services to the urban and rural elderly. *Journal of Gerontological Social Work* 6: 3-23.
- Older Americans Act of 1965. 42 U.S.C. 3021 et seq. Section 306 (a) 1.
- Ory, M., R. Hoffman, J. Yee, S. Tennstedt, and R. Schulz. 1999. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist* 39: 177-183.
- Pruchno, R., and S. Postashnik. 1998. Caregiving spouses: Physical and mental health in perspective. *Journal of the American Geriatrics Society* 37: 697-705.
- Scharlach, A., B. Sirotnik, S. Bockman, M. Neiman, C. Ruiz, and T. Dal Santo, 2003. *A profile of family caregivers: Results of the California statewide survey of caregivers*. Berkeley, CA: University of California, Center for the Advanced Study of Aging Services.
- Scharlach, A., T. Dal Santo, J. Greenlee, S. Whittier, D. Coon, K. Kietzman, K. Mills-Dick, P. Fox, and J. Aaker. 2001. *Family caregivers in California: Needs, interventions and model programs*. Berkeley, CA: University of California, Center for the Advanced Study of Aging Services.
- Schulz, R., and S. Beach. 1999. Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association* 282: 2215 – 2219.
- U.S. Census Bureau. 2000. *Census 2000 of Population and Housing*, Summary. File 1.
- U.S. Census Bureau 2000. State and County Quickfacts. U.S. Census website. Retrieved September 18, 2003, from the World Wide Web: <http://quickfacts.census.gov/qfd/>
- Wachs, M. 2000. *Mobility for California's Aging Population*. Berkeley, CA: University of California, California Policy Research Center.

Williams, R.L., and K. Yanoshik. 2001. Can you do a community assessment without talking to the community? *Journal of Community Health* 26: 233-247.

Zarit, S. 2001. *Respite services for caregivers* [online]. Washington, DC: Administration on Aging [cited 19 September 2001]. Available from World Wide Web: (<http://www.aoa.gov/carenetwork/ZaritMonograph.html>)

Table 1:

Number of Service Providers Identified by AAAs and Internet Search that Offer Each of the Title III-E Caregiver Services

	AAA (n=304) N (range)	Internet (n=195) N (range)	Total N
Information	107 (0-10)	95 (0-10)	202
Access	79 (0-9)	64 (0-5)	143
Counseling	76 (0-10)	49 (0-16)	125
Respite	190 (0-23)	104 (0-16)	294
Supplementary	82 (0-9)	87 (0-15)	169

Caregiver Support Services

Table 2:

Proportion of AAAs Identifying Service Gaps by Each Title III-E Caregiver Service Type

%	Information
75	Multilingual/culturally appropriate information
46	Outreach
42	Community education classes
42	Financial/legal planning information
Access	
75	Transportation
67	Multilingual/culturally appropriate access
63	Financial assistance
58	In-home workers in rural areas
54	Rural community services
Caregiver Support	
54	Multilingual/culturally appropriate services
46	Peer counseling
42	Retreat
Respite	
79	Multilingual/culturally appropriate services
79	Emergency respite
58	Overnight respite
50	In-home respite
42	Adult day care
42	In-home worker registry
Supplemental Services	
50	One time emergency cash
46	Multilingual/culturally appropriate services
38	Chore/homemaker
38	Emergency in-home help
38	Home-delivered meals